

Health Status Condition on Children with Leukemia Through Family Centered Empowerment Model

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ABSTRACT

Family-centered empowerment (FACE) is a nursing intervention by increasing family filial values, which consist of responsibility, respect, and family care. The objective of the study applied a family-centered empowerment model (FACE) to the health status of children suffering from leukemia. The study used quasi-experiment design, with the sample being 30 families with children suffering from leukemia treated in Soetomo Hospital Surabaya. Independent variable is family-centered empowerment (FACE) model and the dependent variable is health status condition of children suffering from leukemia. There is influence of FACE model to health indicator of children suffering from leukemia, consisting of child weight $p = 0.000$ (<0.05), leukocyte $p = 0.002$ (<0.05), and bleeding incidence $p = 0.041$ (<0.05). The Family Centered Empowerment (FACE) model is applied to families with children suffering from leukemia by nurses as an intervention of family filial value enhancement in increasing responsibility, respect and care so that families can develop their family appraisal skills to provide the best care while facing the challenge of treating children with leukemia. The family-centered empowerment model can improve family ability in treating children with leukemia, which impacts on child health indicator.

Keyword: Family, Empowerment, leukemia, children

Introduction

Leukemia is a blood cell malignancy originating from the bone marrow, characterized by the proliferation of white blood cells, with manifestations of the addition of abnormal cells in peripheral blood. The rapid change in symptoms in patients with leukemia causes children to feel great pain.¹ Children who suffer from leukemia really need serious attention for a long time, commitment, and it is a hard struggle for family members who care for them.² Caregivers or families who have children with chronic conditions are faced with demands, challenges, emotional and cognitive problems, and changes in roles in family and society. This has an impact on family sustainability in providing care for children, especially in the maintenance phase of the treatment of acute

lymphoblastic leukemia (ALL). One of them is family disobedience in following the treatment process set by the doctor. Families of children with chronic disease conditions often feel helpless in meeting their children's healthcare needs and in sustaining their family life. The helplessness experienced by the family will affect their ability to support providing care for their children. This has an impact on the health status of children suffering from leukemia.

Therefore, an intervention is needed to empower families in caring for children suffering from chronic diseases.³ The family's ability to care for children with leukemia is very necessary to improve their quality of life and, as such, nursing interventions in an effort to improve the family's ability to care for sick children are very important. Cancer in children has become a global problem because its incidence continues to increase, especially in developing countries. In Pakistan, 60% of children die of cancer. The 2013 Basic Health Research (Riskesdas) showed the Special Region of Yogyakarta (DIY) was the region with the highest prevalence of cancer patients in Indonesia for all ages based on a doctor's diagnosis of 4-5 per 1,000 residents.⁴

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Based on the estimated number of cancer patients, Central Java and East Java Province are the provinces with the highest estimate of cancer patients, which is around 68,638 and 61,230 people, respectively. The average cancer prevalence in Indonesia is 1.4 per 1.00 population.⁴ Based on the register of the Division of Hematology & Oncology, SMF, Pediatric Dr. Soetomo Surabaya obtained data that, in 2016, there were 252 new cases of children diagnosed with cancer, the most number being Acute Lymphoblastic Leukemia (ALL) with 108 new cases.

Family empowerment is an intervention that nurses can use to help families.⁵ el autor desarrolla una reflexión sobre el empoderamiento como una orientación valórica para el trabajo en la comunidad, y por tanto el empoderamiento como un enfoque necesario para procesos de transformación social. En este sentido, Zimmerman toma aportes de diversos autores para concluir que el empoderamiento sugiere un enfoque distinto para el desarrollo de intervenciones que se orienten hacia el cambio social. Así, dirige la atención hacia los recursos y capacidades de las personas y sus comunidades, y explica los principales problemas sociales producto de la desigualdad en la distribución y acceso a recursos. Finalmente el autor propone redefinir la relación profesional con la comunidad que se interviene. Así, el profesional pasa de ser experto a facilitador de procesos, y los miembros de la comunidad pasan de ser sujetos pasivos a colaboradores en los procesos de diseño, implementación y evaluación de una intervención. A continuación, se describe el empoderamiento como modelo teórico, el cual requiere la comprensión de múltiples niveles de análisis para comprender el proceso y las consecuencias del empoderamiento en la calidad de vida de los individuos, sus organizaciones y comunidades. Finalmente, el autor examina la construcción del empoderamiento en tres niveles: (a) This interactive intervention is designed to help families through the empowerment process, which consists of several stages that can increase the trust and decision-making of families to be able to work with health professionals. Activity activities are based on the assumption that everyone has the strength and capability and capacity to grow and become more competent.

Family empowerment is influenced by several factors, including the demands of care, family factors, patient factors and health worker factors, in this case, nurses.⁶

The constituent attributes of family empowerment can be assessed from self-efficacy, motivation, acceptance of threats, responsibility, respect, and care.

The expected results in families with such empowerment are the ability to cooperate with health professionals, minimize the effects of chronic conditions on children and siblings, restructure family roles and responsibilities, satisfy children's healthcare needs, and reduce healthcare use and costs, so that, in the end it is expected to increase the health status of children with leukemia.

Method

Study Design, Setting, and Sampling: This study uses a quasi-experiment design. The sample used in this study was 30 mothers with children suffering from leukemia who were treated at the Children's IRNA Dr. Soetomo Surabaya Indonesia, which was divided into two groups, namely 15 treatment group respondents and 15 control group respondents. The independent variable in this study is the Family Centered Empowerment (FACE) module and the dependent variable in this study is the family's ability to treat leukemic children and the condition of the health status of children with leukemia. Indicators in family capacity measured were perceived health, personal growth, and existential wellbeing, while the children's health indicators measured were nutritional status, secondary infection incidence, and bleeding events. Data were analyzed using parametric pair T-test and independent t-test.

Result

In the treatment group, the average value after treatment was higher than before treatment, even though the increase had not reached 10% of the average value before treatment (Table 1). The results of statistical tests showed a significant difference between family abilities before and after treatment. The highest difference is the personal growth indicator, which is the mother's perception of her condition and which includes the development of positive life skills, and realistic and healthy self-development. These results indicate that the FACE module can improve the family's ability to care for leukemic children, especially the ability of the family, in this case the mother's ability to manage desired expectations, and planning actions to help achieve goals

while caring for leukemic children. In the control group, it can be explained that the average value before and after also increases with the average increase smaller than the treatment group. Based on statistical tests, it was found that there were no differences in family abilities in treating leukemic children in the control group. Based on the results of statistical tests of differences between the treatment group and the control group, there was a difference in the average value of the family's ability to treat leukemic children. The average value of the family's ability to treat leukemic children in the treatment group was higher compared to the control group. This shows that the application of the FACE module can improve the family's ability to care for leukemic children, which includes perceived family ability (personal health), personal growth and existence for prosperous conditions (Existential wellbeing).

The average value of health indicators of children suffering from leukemia, in this case BB, leukocyte value, and the occurrence of bleeding, in the treatment group shows an increase in health indicators, namely the average value of child BB increases, the average value of leukocytes in the normal range, and the frequency of bleeding; on average, there is a rare bleeding category

(Table 2). Statistical tests show that there are significant differences between the indicators of children's health before treatment and after treatment. This shows that the application of the FACE module to the family can improve the health indicators of children with leukemia.

In the control group, it can also be explained that there was a change in the average value of health indicators for children suffering from leukemia, but the change in the average value in the control group was lower than that of the treatment group. The results of statistical tests show that there are differences in the health indicators of children with leukemia on leukocyte values, and there is no difference in the indicators of body weight and the frequency of bleeding.

Based on the statistical analysis of the differences between the health indicators of children with leukemia in the treatment group and the control group, it was explained that there was no difference between the indicators of health of leukemic children in the treatment and control groups. It can be explained that the administration of the FACE module in the treatment group can improve the health indicators of children suffering from leukemia, especially in increasing body weight and decreasing the frequency of bleeding.

Table 1: Pre-Post Values of Family Ability to Take Care of Leukemic Children in IRNA Child Hospital Dr.Soetomo Surabaya

No	Indicator	Mean \pm SD treatment			Mean \pm SD control			Different test		
		Pre	Post	p	Pre	Post	p	Pre-Pre	Post-post	Δ
1.	Perceived health	30.73 \pm 3.92	33.60 \pm 2.197	0.004	28.60 \pm 2.293	28.73 \pm 1.580	0.825	0.079	0.000	0.000
2.	Personal Growth	23 \pm 7.783	28.27 \pm 3.955	0.002	22.80 \pm 4.678	25 \pm 2.752	0.089	0.933	0.017	0.000
3.	Existential wellbeing	28.93 \pm 5.077	33.27 \pm 3.973	0.000	24.87 \pm 5.527	26.40 \pm 5.654	0.077	0.084	0.001	0.000

Table 2: Pre-Post Value Indicator for Child Health Leukemia in IRNA Child Hospital Dr.Soetomo Surabaya

No	Indicator	Mean \pm SD treatment			Mean \pm SD control			Difference test		
		Pre	Post	p	Pre	Post	p	Pre-Pre	Post-post	Δ
1.	Weight	12.93 \pm 2.764	13.69 \pm 2.461	0.000	17.29 \pm 6.088	17.39 \pm 6.086	0.150	0.27	0.045	0.000
2.	Leukosit	7373.3 \pm 3295.08	6266,0 \pm 2623.79	0.002	7916.80 \pm 2229,56	6672.67 \pm 1799,668	0.001	0.601	0.596	0.742
3.	Incidence of bleeding	4.13 \pm 1.302	3.87 \pm 1.06	0.041	4.40 \pm 1.454	4.27 \pm 1.335	0.164	0.944	0.371	0.369

Discussion

The results of the study showed that family abilities significantly influence children's indicators. The family capacity in this study includes the results of family care indicators in caring for leukemic children, which consist of perceptual indicators about managing health, personal and family growth, and the existence of prosperous conditions.

The results showed that the majority of respondents were in the medium category on each indicator of parenting results, with the highest category on the indicator of family ability, in this case how the mother manages her health while providing care for leukemic children. The highest low category is an indicator of family ability to maintain the condition of existence of wellbeing while caring for children with leukemia. This shows that the family's ability to treat leukemic children still needs to be improved.

The existential condition of welfare conditions (existential wellbeing) can be influenced by several factors, one of which is age.² In this study, the age of the mother was mostly in the category <35 years (early adult). The life cycle in the early adult category, according to Ericson, is in the phase of generativity vs. stagnation. One of the tasks that must be achieved is to be able to devote themselves to achieving a balance between the nature of giving birth to something (generativity) by doing nothing (stagnation).⁷ Failure to improve the ability to give birth to something will cause stagnation in the family in providing care to a sick child. This is what can reduce the ability of the family to maintain welfare conditions in them.

The indicators of children in this study were the nutritional status of children, the incidence of secondary infections, and the occurrence of bleeding. Cancer and its treatment can affect energy intake and its use.⁸ The results showed that most child health indicators were in the moderate category. Indicators that have the highest good category are in indicators of nutritional status. This shows that the family's ability to treat leukemic children is more visible in how parents improve their ability to meet the nutritional needs of children suffering from leukemia. Increasing family capacity in caring for children with chronic conditions is influenced by family knowledge and experience.⁹ The results of this study indicate that the ability of mothers to meet children's

nutritional needs can be seen in the indicator of increasing body weight of children suffering from leukemia. There are several factors that cause malnutrition in children with cancer, including: a) specific factors for tumors; b) factors related to patients; and c) factors related to treatment.¹⁰ The results also showed that children's indicators of secondary infection aspects seen from laboratory values of leukocytes in children showed differences before and after intervention to mothers in improving their ability to care for leukemic children, even though the difference was not significant for changes in leukocyte values, but still within the limits normal. The description of laboratory values in children suffering from leukemia varies from mild to severe. The laboratory results are influenced by the age of the child. Likewise, for child health indicators that are seen from the frequency of bleeding events, based on the results of the study, there are differences in the decrease in the frequency of bleeding events before and after the intervention. Decreasing the incidence of infection and bleeding events is supported by the fulfillment of optimal nutritional needs carried out by the mother and can also be caused by the treatment process undertaken by children suffering from leukemia.

The family's ability to care for leukemic children requires an effort made by health workers so that the family's ability to care for leukemic children increases and children's health indicators can also be improved.

Conclusion

The Family Centered Empowerment (FACE) model that is applied to families improves the health indicators of children with leukemia, which includes increased child weight, decreased incidence of secondary infection with indicators of leukocyte value stability, and decreased incidence of bleeding frequency. It was found that the FACE model for improving the ability of families to care for leukemic children found can be applied in families as one of the nurses' references in providing child nursing care in chronic disease conditions.

Ethical Clearance: This study was stated as ethical conduct according to as stated in the ethical certificate issued by Dr. Seotomo Surabaya number 385/Panke. KKE/V/2018

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